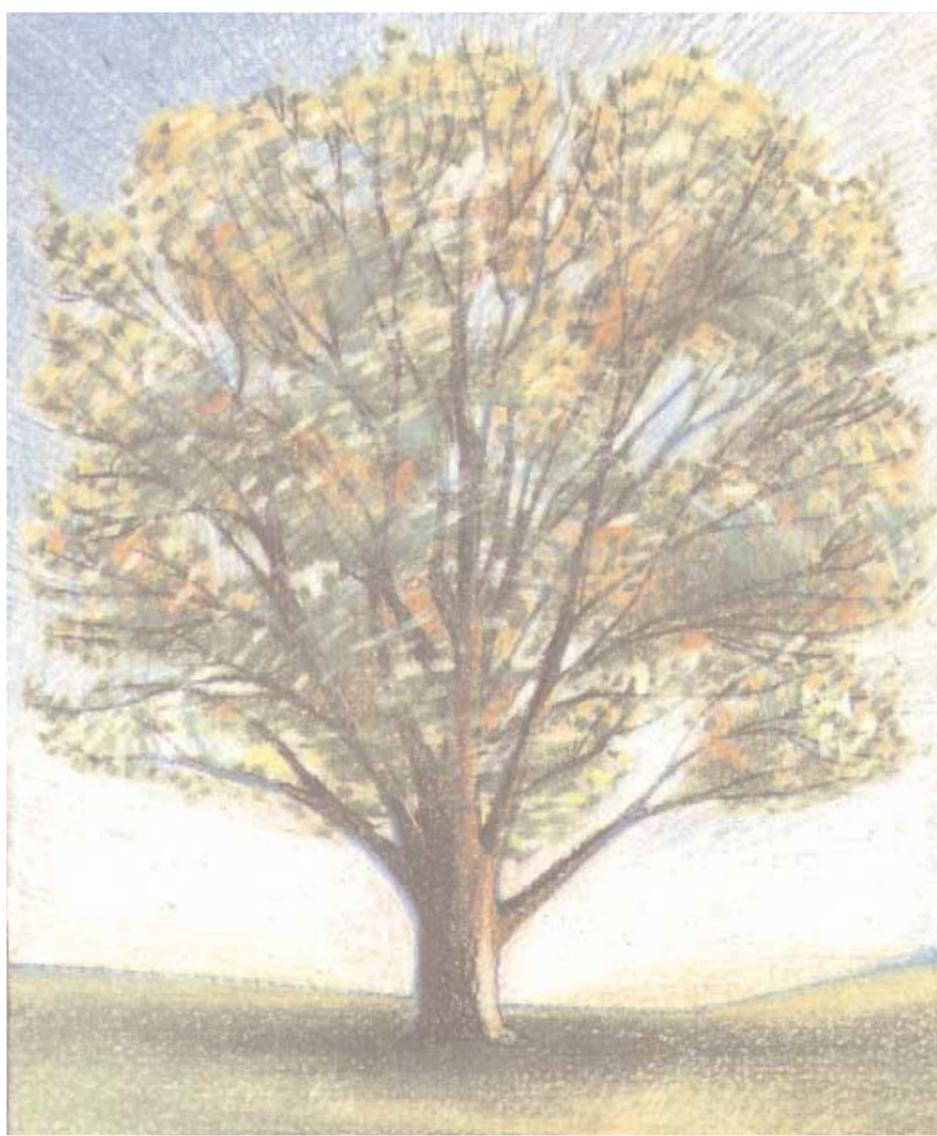


Advanced Cancer

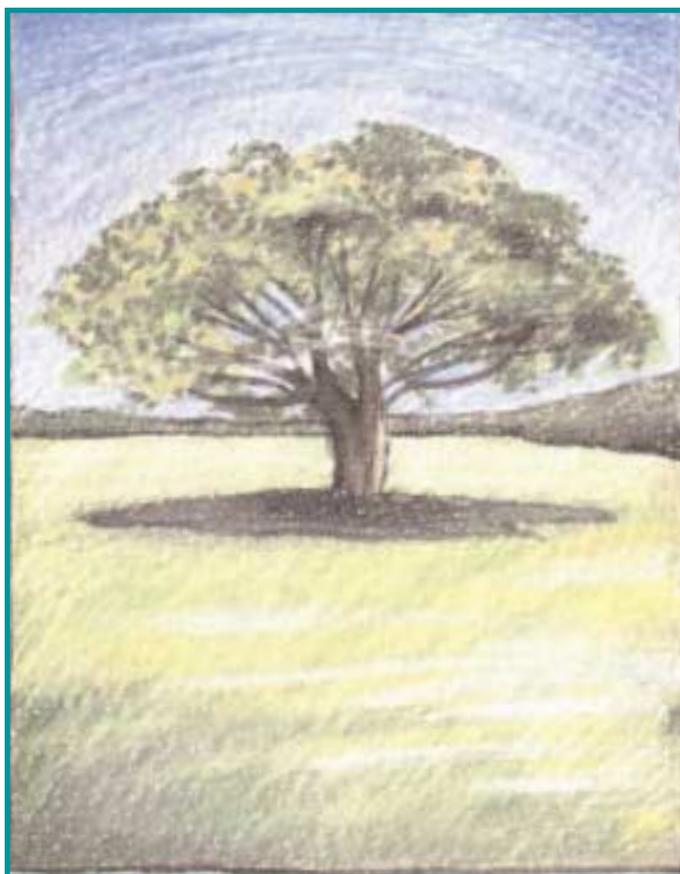
LIVING EACH DAY



NATIONAL INSTITUTES OF HEALTH
National Cancer Institute

Advanced Cancer

LIVING EACH DAY

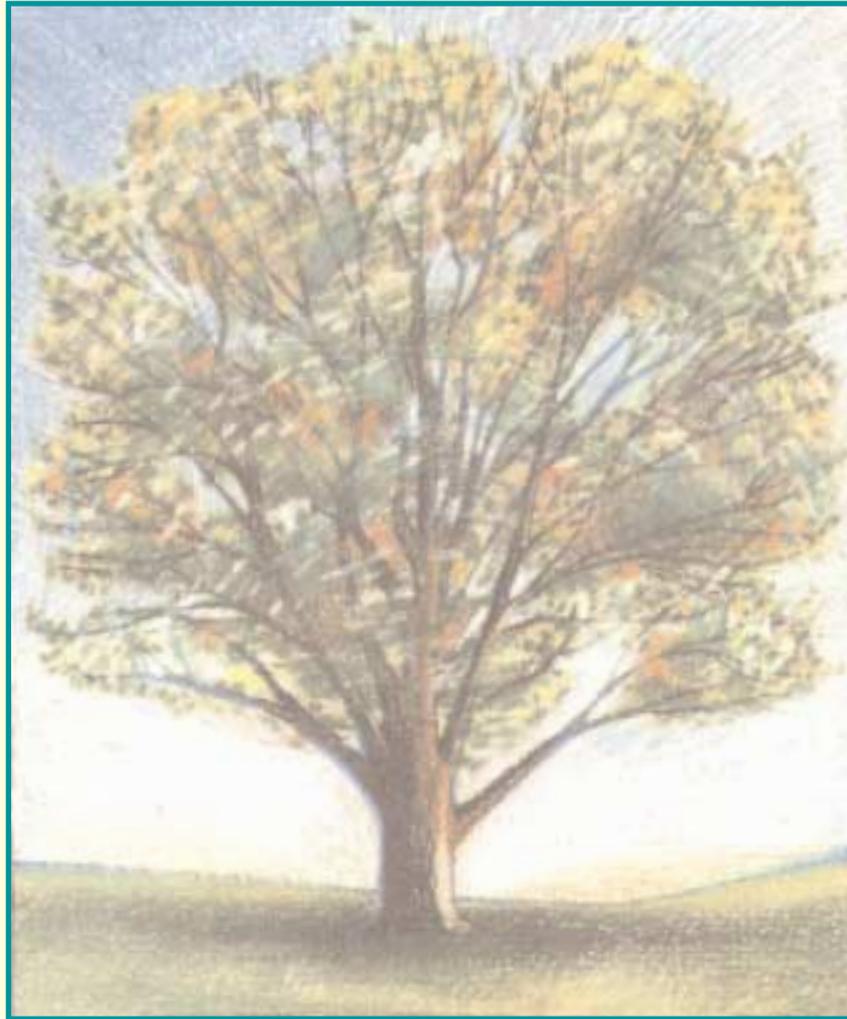


U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health

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Introduction

This National Cancer Institute booklet was written to help persons who have gone through the struggles of diagnosis, treatment, and, perhaps, recurrence of cancer, persons for whom a cure or long-term remission is no longer likely. Terms that doctors use for this stage of illness are advanced, terminal, or end-stage disease. Although these terms can have different meanings, they are used interchangeably in this booklet.

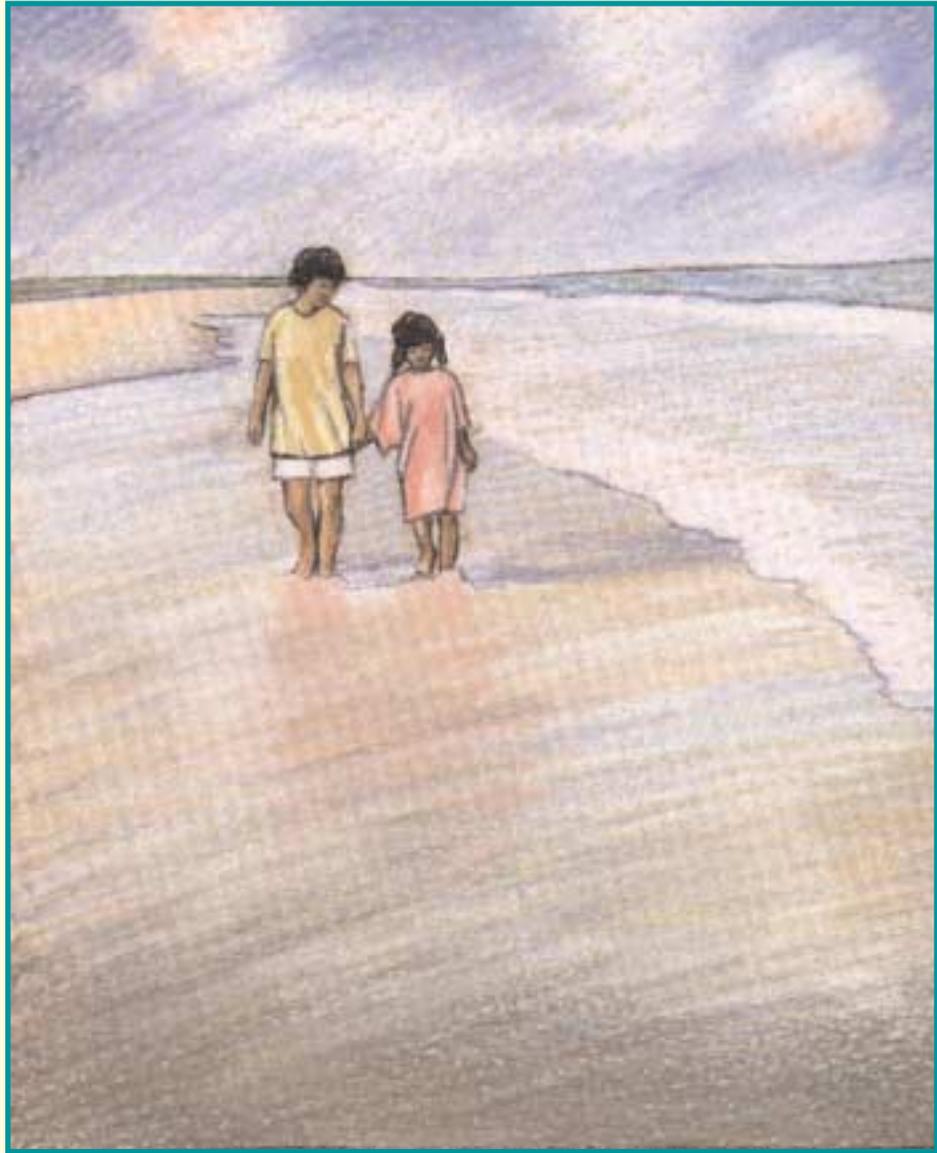
Advanced Cancer is meant to help people who are facing death from cancer live their remaining days as well as they can. It is based on the most current information available and on interviews with patients, their families, and their caregivers.

Throughout the booklet, several themes are stressed:

- Many of your concerns can be eased with medical skill, support from caregivers, and knowledge about your illness.
- Talking with others about your anxieties, frustrations, concerns, and problems may be one of the best things you can do for yourself.
- Loss of control over your illness does not mean loss of control over the days ahead. You can choose the way you wish to face each day.

Some of the information in this booklet may not be suitable for all readers. As you read this booklet, select the parts that are right for you. Please keep in mind that Advanced Cancer was written primarily for adult patients and their families. If you are a parent, relative, or friend of a child or young person who has terminal cancer, you may wish to call the National Cancer Institute's Cancer Information Service for more information (see page 39).

We hope that this booklet will help ease your concerns. Perhaps it will show you that each day can be meaningful and offer comfort, sometimes in a new or unexpected way. Even at this difficult time, there are many things that can be done to help you lead a dignified, satisfying life.



Living One Day at a Time

Few people like to think about dying. We all know that death will come, but most of us spend little time thinking about it.

Approaching death often brings a change in how we look at life and what we value. For many people, having a serious illness leads them to live one day at a time rather than to put off until tomorrow, next week, or next year what could be done or said today.

One patient expressed his philosophy this way:

“The death rate for any generation is 100 percent. We all die. However, I know what probably will kill me, while most people don’t. We have no guarantee of how long we will live. But I believe it is truly the quality of life, not the quantity, that is most important.”

There is no right or wrong way to face the end of life. Do what is most comfortable and useful for you. Many people with a serious illness are able to find peace of mind by coming to terms with their emotions and beliefs about life and death. You may be able to find meaning for yourself, in your own way and at your own pace.

The Will to Survive

We are all born with the will to survive. Exactly what influence this has on diseases — especially cancer — has been debated for a long time. But there is little argument that a strong desire to live can enhance the quality of life.

Many people with terminal cancer have lived far longer than expected. They often share a positive attitude about the value of life. They also seem to have a combination of hope, endurance, willpower, and courage. When asked to explain how they have managed, they often give answers such as, “I’m needed too much at work,” or “I can’t die until my grandchild is born.” They do not want to give up or retreat from living. A keen interest in daily events helps to get them through uncomfortable treatments or disease-related problems.

This does not mean that a positive attitude alone necessarily will lengthen your life. Nor does it mean that you are doing something wrong if you are sick and not getting better. But emphasizing the positive aspects of your life can add meaning, purpose, and comfort to your remaining time.

How You May Feel When Time Is Limited

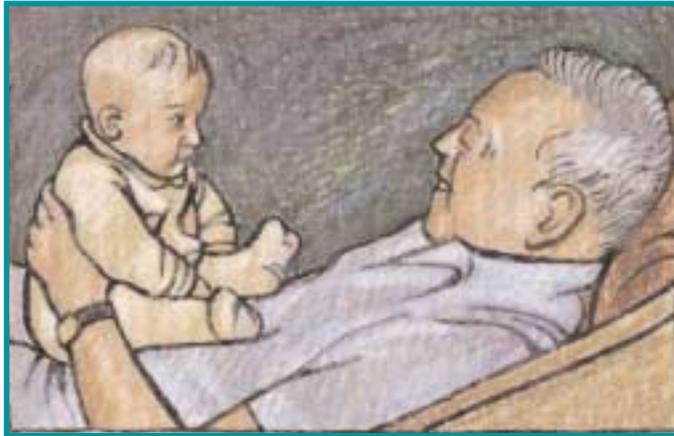
Each of us is unique, and we each find our own way to live and die. Still, many patients with advanced cancer have many feelings in common and may approach this time in their lives in similar ways.

You may not experience all the emotions discussed in this booklet or in the exact way they are described. Your feelings may come, go away, and then come again. Information is presented to reassure you and those close to you that your reactions are not unusual; they are a part of the way we, as humans, make peace with ourselves.

When patients are first told or first realize that their cancer can no longer be treated effectively, they often react by denying that this could be happening to them. They believe they will find a way to beat the odds. This is a way of coping with an overwhelming situation, and it may be helpful at first. With time, however, patients and their loved ones are often able to face reality. One patient explained it this way:

“The reality of death does not go away by denying it. When you do this, you can miss the comfort you get from sharing fears and concerns. You miss the sense of well-being you get knowing you have taken care of your loved ones.”

The feeling of “No, not me!” often changes to “Why me?” This question may result from feelings of anger and rage. You may be angry with the doctor, family members, neighbors, your disease, and even yourself without good cause. This is a normal reaction, and with some time, if you can accept and understand your anger, hopefully it will pass. It may help to talk about your



feelings with your family, a close friend, or a social worker. It also may help to keep in mind that you are not responsible for your disease.

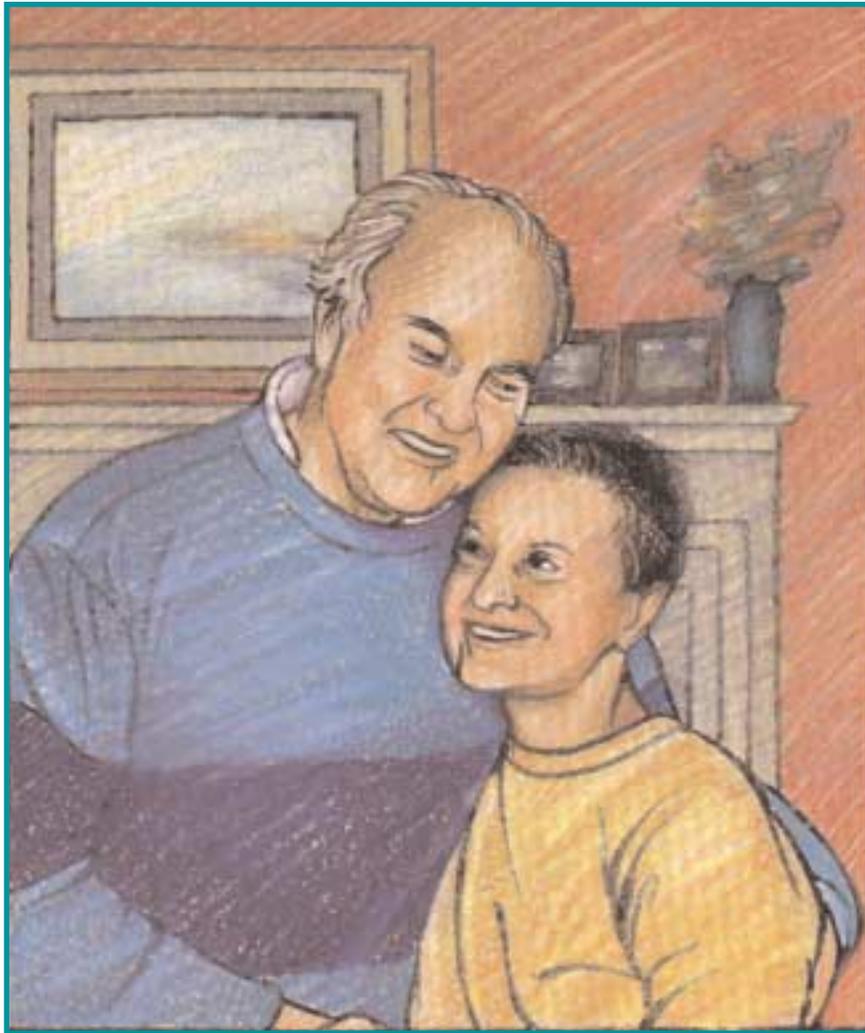
Next you may begin to realize that there is no answer to the question, “Why me?” Your anger is not the solution, and you may find yourself “bargaining” for a longer life. People make all kinds of promises in hopes of a longer life. A promise might be “If I can live just one more month, I’ll go to church every day,” or “If I just can see my son married, I won’t ask for more.”

It is not unusual to bargain. In fact, taking notice of what you ask for and then working to accomplish your wishes may help relieve some anxieties about things left undone and words left unsaid.

At times you may feel depressed because you have lost control of some aspects of your life or your independence. It may help to focus on what you value most in life — family, friends, or other things that you cherish — rather than on what you cannot change.

As your illness progresses, depression from losses that already have occurred may give way to grief over the people and life you are going to lose. This grieving should not be discouraged; it must be worked through to gain peace of mind and acceptance. Frequently, talking through these feelings with a loved one, clergy, social worker, counselor, or support group can ease the grieving process.

During this time, you may find yourself wanting to have fewer people around. It may help you and your family and friends to understand that this type of withdrawal often occurs toward the end of life. Conversation may not be needed as long as someone who cares for you is nearby. A smile or a gentle touch sometimes can say much more than words.



Not all people who face the end of life are able to find peace and accept death; however, with time and support from those around you, acceptance is often possible. You need to know that everything that can be done for your peace and comfort will be done. Don't be afraid to ask for such support and assurances.

Your Inner Strength

Most people are overwhelmed emotionally when they first learn that their cancer no longer can be controlled. They may not be able to cope as well as they did in the past. Sometimes they may temporarily lose their will to live, but their reactions often change with time.

Your feelings of hopelessness may change because of physical and emotional reserves you didn't know you had. Calling on your inner strength can help revive your spirits and your drive to enjoy each experience and each day. Concentrating on the present instead of the future can be helpful. For many patients, the future becomes the end of each day. As one person explained:

“Before this happened I had a 5-year plan, a 10-year plan, even a 20-year plan. No more. What I realized was that I could only die in the future, but I was alive right now, and I always would be alive in the here and now.”

Others prefer to plan ahead—days, months, even a year or so. This reaffirms to themselves and others that they are not finished with living and accomplishing goals. With places to go and things to do, life stretches before them.

Your plans may involve doing things that you enjoy each day. You may want to plan a few “special days” with family members or friends—a day outing, a concert, or an afternoon together. Or you may want to focus on fulfilling a lifelong dream, such as taking a trip. Without a plan, whether it is general or very specific, you may find that your time consists only of routine daily activities. But try not to do too many activities. Becoming tired may weaken your defense against depression and despair and may make coping with your illness more difficult.

Some people view their illness as a challenge to be met or a battle to be fought. They think of each day they survive as a victory. One woman expressed her outlook this way:

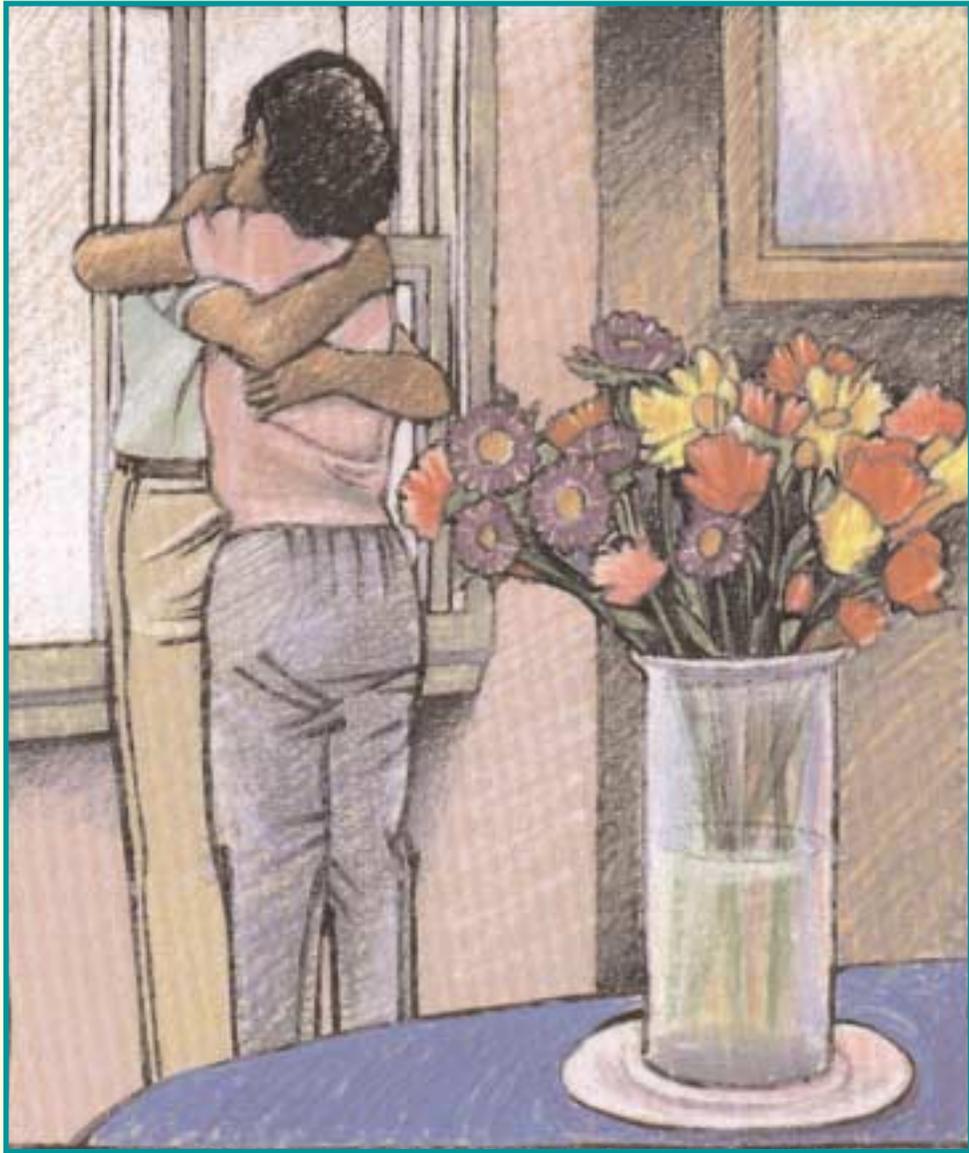
“I get satisfaction by being engaged in the fight. It’s me and my doctors against the cancer, and we know we might not win in the end. But by God, we’re going to give it a run for its money.”

Others cope by rethinking what is important in their lives and what is not. As one person said:

“Disease rearranges your values, and you cast off things. You reduce the trivia to a minimum; you simplify life.”

It may be helpful to put together a “living legacy” — a book, cassette, video, piece of artwork, or poem that reflects who you are — to share with your family and other loved ones.

However you choose to cope, your inner strength can help you live each day as fully as possible.



What You Can Do for Yourself

Living with a serious illness can be discouraging. You will have good days and bad days, just as you did before, and your ability to deal with these changes may vary. In the morning you may feel down, but by afternoon your outlook may improve. On one day, you may have little energy, but on another, your mood and spirit may rebound. During the bad times, try to remember the good moments and remind yourself there can be more good times ahead.

Taking charge of your life is one way to help yourself. Take an active role in the kind of care you receive. Participate in daily activities with your family and friends.

Do things for yourself that make you feel good, such as attending religious services or encouraging visits from friends. Let others help you. Let them know what they can do for you and what you can do for yourself. They will be grateful for specific suggestions. Your caregivers may recommend things that don't seem as important to you now, such as exercise, medications, and food. But these measures will help you keep your strength and independence for as long as possible. Working with your caregivers and family helps you maintain a sense of control, purpose, and hope.

Set the tone for those around you. Making those around you feel comfortable now will help them to be comfortable around you throughout your illness. As one patient said:

“You have to do this because no one knows how you want to be treated, and they may be waiting for a cue. No one else will talk about it unless you do.”

At the same time, remember that you don't have to be noble and heroic if you don't feel that way. Sometimes loved ones may want you to try to keep your feelings of sadness or anger inside because they can't face their own painful emotions; however, your feelings are important and need to be shared.

Facing the Challenge

It may be very hard to accept that your body is no longer as strong and reliable as it once was. As cancer progresses, you will not be as independent as you once were. This new dependence on others may affect your self-respect.

Your role in the family and at work will change as well. When this happens, remember that the qualities that made you a good friend, loving parent, caring mate, or responsible worker haven't changed.

One woman had this to say about her feelings about herself:

"It shouldn't take a fatal diagnosis to find self-awareness, self-concern, and self-love. But, I'm afraid, for most of us, it does. I think I've straightened myself out in these areas. In fact, I've discovered that I'm a stronger person than I might have anticipated. I am just a bit gutsier than I thought, and I'm delighted to know that about myself."

You may be able to continue many of your regular activities, such as playing sports, doing volunteer work, or traveling. Advances in the ability to control pain and to administer needed medications and treatments outside the hospital can give those in the later stages of cancer more independence while receiving medical care.

Arranging family albums, scrapbooks, or hobby collections; working on a computer; or keeping a daily journal of your feelings and experiences are activities you can do if you are less active. Just remember to conserve your strength for the activities you really want to pursue.

Keep in mind that you can have control over many aspects of your life whether you are bedridden or not. You can make decisions about your care, your activities, food preferences, and what you need to make yourself comfortable. In the hospital, for example, you can wear your own clothes or use your own blanket and pillow. In some cases, you also may be able to participate in decisions about your schedule for resting, bathing, and so on.

Maintaining independence makes many patients feel better about themselves. However, well-meaning family and friends may try to make decisions for you, and sometimes you must rely on others for your care. When you face situations such as these, just remember: You know better than anyone what you need to make the most of each day.

Handling Your Emotions

As mentioned earlier, people who are dying from cancer may be sad, depressed, angry, scared, or all of these. These feelings are very human and natural. You already may be grieving for the loss of the person you were before you had cancer. As your friends will grieve for you, you now may be grieving for your loss of them.

You may be wondering what experiences you will miss in life, what the moment of death will be like, and whether you will continue to “be” after death. You may think about what will become of your family and friends and how these people will react to your death.

Don’t bottle up your emotions. Letting feelings out will help relatives, friends, and caregivers understand your needs; may relieve some of your sadness, depression, or anger; and even may reduce physical discomfort. For some people, writing about emotions can help, and occasionally you may want to punch a pillow, scream, or have a good, long cry. Go ahead and express your feelings.

If you are feeling angry, it will help both you and others to understand that your anger may not be meant for them. You might even think of ways to make your anger work for you. For example, perhaps you can focus your energy on changing some aspect of your care that displeases you.

Many people with a terminal illness develop an interest in expressing or trying to resolve spiritual or religious issues. Even if you don’t consider yourself a “religious person” or haven’t taken part in religious services, you may find comfort in exploring spiritual matters with a friend, family member, or member of the clergy. For some, prayer and/or meditation can be a positive spiritual boost.

Talking It Over

Honest and open communication about your illness can help you in several ways. It can help those close to you understand how you want to be treated, and the weight of your problems may be lightened just by talking them over with a family member, a friend, or other cancer patients who may think of ideas to help comfort you. Sharing your feelings also may reduce stress.

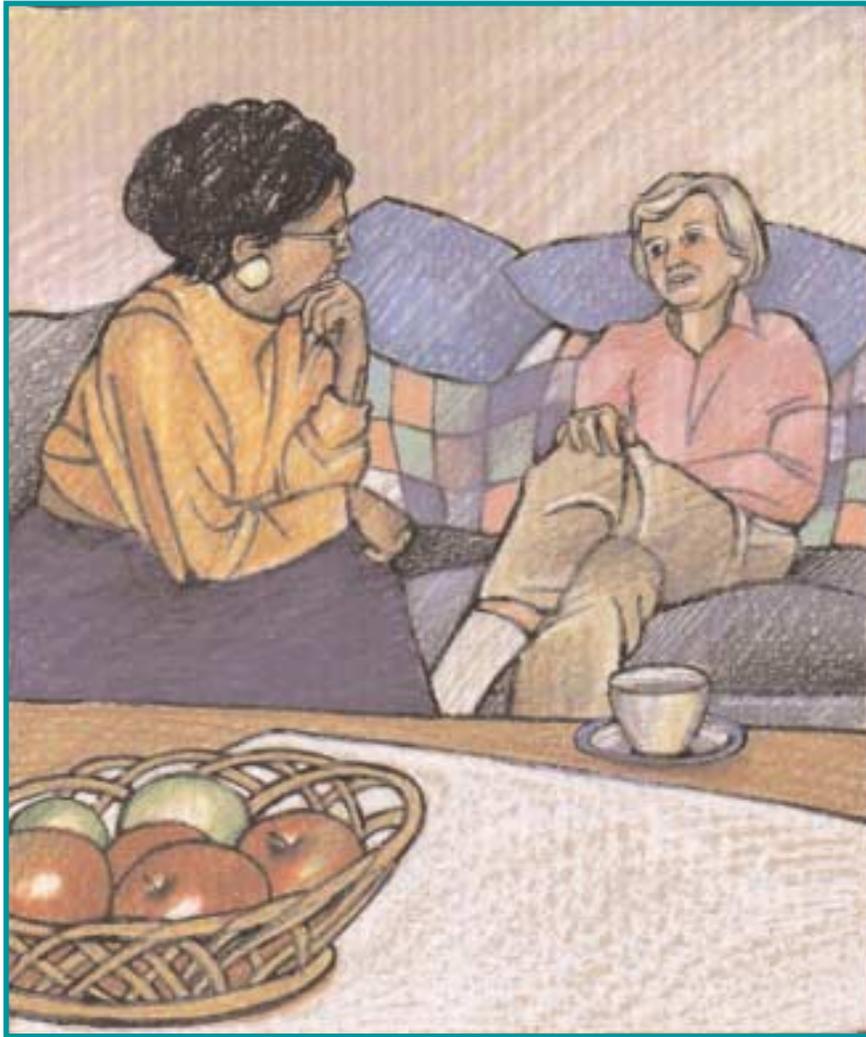
You may find this kind of communication difficult, and it may be hard for others. Still, talking over your worries and concerns and knowing how your loved ones feel can give you strength and reassurance. To discuss these issues, try to choose people who are comfortable with your illness.

Let your friends and relatives know that they can offer comfort simply by being themselves, by listening without trying to solve problems, and by being at ease with you.

But keep in mind, not everyone can handle your suffering and loss. Friendships and family relationships may change — not because of you but because others may not be able to cope with their own emotional pain about your illness. If this is the case, you might want to talk to a member of your medical team or to someone trained in counseling, such as a nurse, social worker, psychologist, member of the clergy, or, if you are receiving care at home, a professional home health care worker. Also, you may find support by attending self-help groups where people meet to share common concerns. Your caregivers, hospital or a hospice can help find the right person or group for you.

Making the Unknown Known

Some say it is not death people fear but the days, weeks, or months that precede it. Many are afraid that there will be pain during this time and wonder if they will become a burden. Patients with a serious illness fear the unknown, isolation, abandonment, and loss of physical and emotional control. They worry about the future of those who will outlive them.



Understanding your condition can help you and your family resolve these fears. The more you learn about your condition and treatment, the more your fears of the unknown are reduced. Don't hesitate to ask your doctors, nurses, and other caregivers if there is something you want to know. Remember: It is your right to receive answers, even to the most direct questions about your future.

Sometimes your health care providers will seem hesitant to offer information. They may not be able to explain exactly what

to expect. Or they may wait until you seem ready for the information. You can signal your readiness by asking specific questions — about your life, your illness, and about dying.

Try to include one or more relatives, friends, or others who are supportive in talks with your health care providers. If the health providers explain matters directly to your caregivers, your caregivers gain a clearer understanding of how they can help you, and their concerns can be eased.

Relieving Your Pain and Discomfort

Many people with cancer fear physical pain. However, not everyone with cancer has pain. And those who do have pain are not in pain all the time.

If you have pain, it can be treated. Talk to your doctor or nurse about pain control. Don't wait until your pain is severe. Pain almost always can be lessened.

Cancer patients may have pain for a variety of reasons. Pain may be due to the cancer itself, or it could result from treatment methods. For example, after surgery, a person feels pain as a result of the operation itself. Sometimes, the pain is unrelated to the cancer, such as a muscle sprain, a toothache, or a headache. Whatever the cause, pain can be relieved.

The best way to manage pain is to treat its cause. Whenever possible, the cause of the pain is treated by removing the tumor or decreasing its size. To do this, your doctor may suggest surgery, radiation therapy, or chemotherapy. However, your doctor may be more likely to recommend pain relief methods to control your pain. These methods include pain medicines, operations on nerves, nerve blocks, physical therapy, and techniques such as relaxation, distraction, and imagery.

Many people are reluctant to use pain medications for fear of becoming addicted. But taking medication to relieve pain will not make you an “addict.” In fact, studies show that medically supervised use of narcotics (also known as analgesics) to control cancer pain does not cause addiction. Also, research shows that patients

who take medication to prevent rather than reduce pain, tend to use less medication. And if the cause of your pain can be corrected, you will be able to stop taking your medications.

Physical therapy, biofeedback, relaxation techniques, self-hypnosis, and imagery also may help relieve pain. Other types of pain control include skin stimulation, pressure, vibration, massage, cold or warm compresses, menthol applied to the skin, and transcutaneous electric nerve stimulation. Some of these methods cause nerve endings to become numb in a specific area of the body, providing pain relief without the drowsiness caused by some pain medications. Special procedures that use anesthetics are available for the 10 to 15 percent of patients whose pain therapy is ineffective or causes severe side effects.

You know the most about your pain, such as where it is, how bad it is, what eases it, or what makes it feel worse. Your doctors and nurses rely on you to tell them about your pain. Together, you can decide which methods of relief might be best for you.

Don't hesitate to talk about your pain to your doctor or nurse. You have a right to the best pain control you can get. Relieving your pain means you can continue to do the everyday things that are important to you.

A booklet about handling pain, *Questions and Answers About Pain Control: A Guide for People With Cancer and Their Families*, is available from the Cancer Information Service (see page 39).

Feelings of Isolation

As cancer progresses, your life is disrupted. Social activities with family, friends, or coworkers become less frequent. Routines change because of treatments, visits to the doctor, or your need to rest.

These changes can lead to feelings of loneliness and isolation, even when you are surrounded by family and friends. One way to lessen these feelings is to live as normally as possible. Continue to do the things you always have done, such as hobbies, reading, walking the dog, or enjoying the company of children. Let your family and friends know that you want to continue with life as it

was before. Encourage them, as much as you can, to carry on with their regular routines.

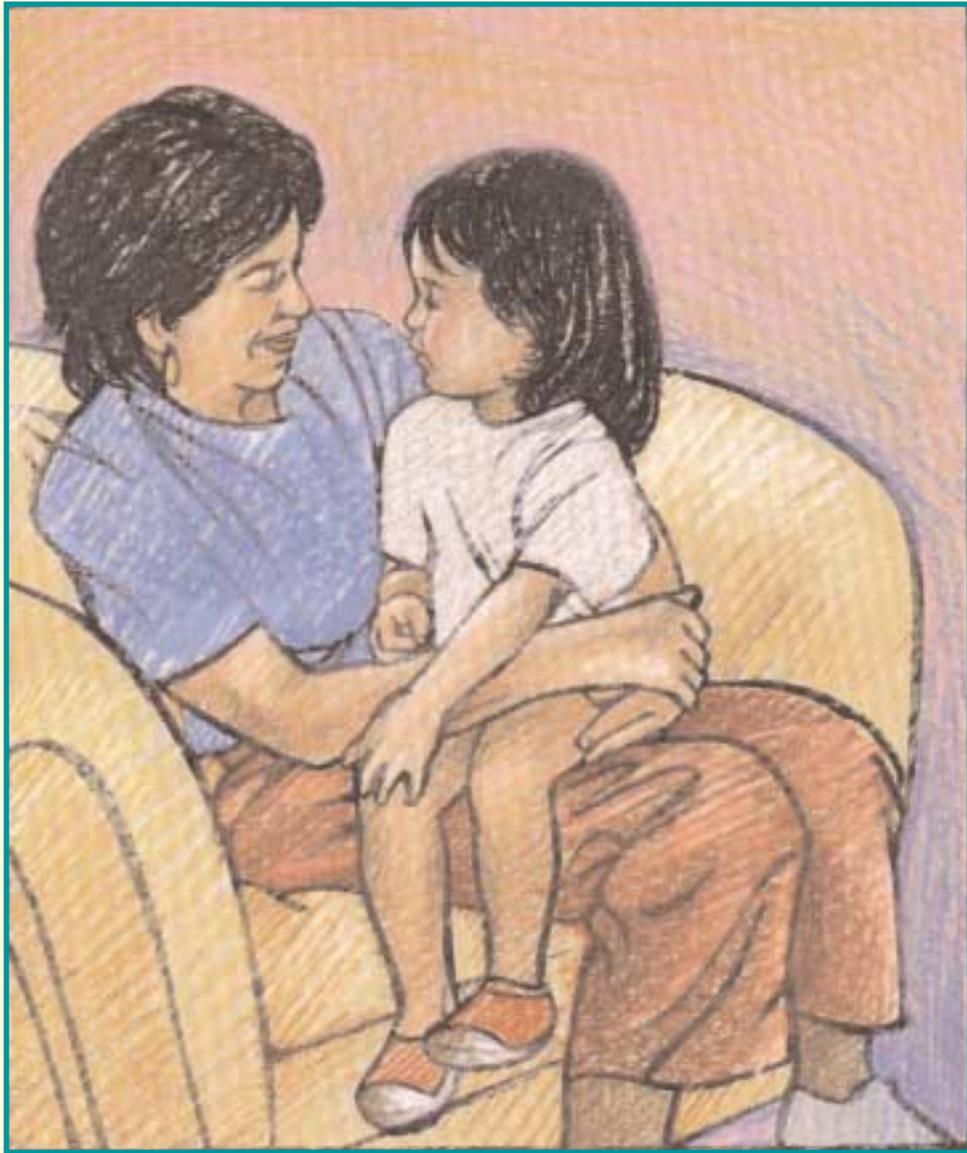
Don't hesitate to ask friends and relatives to visit if you are feeling up to it. They may want to stop by but may be afraid to contact you because they don't know what to say or how to act.

In spite of all your efforts, there will be days when you feel alone because you realize others cannot fully understand or share your experience. Some days you may simply want to be left alone, and that is okay too.

People who live alone or those who do not have family and friends close by may find an illness especially difficult. In these situations, some have found it easier to cope by having volunteers or caregivers visit. For others, the company of a pet often helps.

Talking with other people who have terminal cancer might provide the understanding and companionship you need. Joining a support group, where you can talk with other cancer patients, is another way to ease feelings of isolation.

At times you may need to rely on yourself for encouragement. If this happens, try to focus on the pleasures you can give yourself, such as a leisurely walk, a beautiful bouquet of flowers, or a good book. Draw on your own strength and try to be your own best friend.



The People in Your Life

For many people, family and close friends are the most important sources of emotional support. As one man said:

“My wife and friends who love me are like a circle. They form a protective shield around me. I don’t know what I’d do without them.”

Those who are close to you need understanding as much as you do. It may be helpful to try to consider how they feel and what they can and can’t do. Your loved ones may need time, just as you do, to adjust to your illness and to their feelings of confusion, shock, helplessness, or anger. Letting family and friends know that you want them close and that you need their support will help them cope with these difficult emotions. For many patients and their families, sharing feelings and taking the time to say goodbye provide reassurance and comfort. Don’t hesitate to ask your nurse, social worker, clergy, or counselor to help bring together family members to talk and listen.

How Young and Teenage Children May React

Children whose parent, grandparent, brother, or sister has cancer almost always are aware of a change in their lives. Even very young children sense when something is wrong. They may be frightened by the changes in their daily routine or become angry when someone they depend on is seriously ill. They may worry that they might have caused the illness. It is important to reassure children that nothing they said, did, or thought caused the cancer and that someone will be there to take care of them.

Because of these possible reactions, it is best to be honest and encourage communication. Let your children or grandchildren know that it’s okay to ask questions and that you will answer them as honestly and as thoroughly as you can. Tell children as much as you think they can understand.

Keep in mind that many young people understand more than we can imagine. In fact, children who are not told the truth about an illness in the family often depend on their imagination and fears to explain the changes around them. For example, they may believe that the family member's cancer is punishment for something they have said or done. As a result, they may feel unnecessary anxiety and guilt. Health professionals generally agree that telling children the truth about an illness reduces stress and guilt. If you find it difficult to talk with your children or explain your illness, you might want to ask a close friend, relative, or health care provider for help.

Children need to know that they are still loved and important and that they will continue to be cared for as before. Perhaps a friend can give some time and attention to a child who needs comforting, affection, and guidance. Choose someone the child likes and suggest that he or she help with a special project or attend an important school event if you cannot; ask a friend or family member to videotape your child's performance and then view it with your child when you can enjoy the time together.

Taking the time to listen to a child's triumphs, problems, and fears is important. This holds true for adolescents as well as for younger children. Teenagers are sometimes expected to assume responsibilities beyond their maturity. Try to give them the independence they need, but also be sure to include them as valued family members.

Your doctor or social worker can guide you to an appropriate counselor if you think outside assistance would be helpful. Local hospice counselors also are a good source for helping family members cope.

How Adult Children May React

The potential loss of a parent may change how adult children feel about themselves, may raise questions and fears concerning their own mortality, and may affect their views of what is important in life. Adult children also may be torn by the multiple demands in their lives: roles as parents, children, and professionals. They can experience feelings of guilt about the limited time they are able to spend with you.

Throughout your illness, you and your children may have some of the same emotional reactions. Some of these reactions are shock and depression at the diagnosis; hope that treatment will work; disappointment, frustration, anger, and fear when treatment does not work; and grief associated with the changes and losses that have occurred as a result of the cancer.

As your illness progresses, it will be helpful to share decision-making tasks with your children. Try to involve them in issues that are important to you, such as what type of treatment, if any, you prefer or what types of activities you would like to continue. Sharing these tasks with your children can minimize conflict and fears that may arise between siblings when other important decisions need to be made.

Your ability to reach out to your children and openly share your feelings, goals, and wishes will help them through this time. It also will allow them to feel that they have contributed positively to making this part of your lives together the best possible. It may help to remember that just as parents want the best for their children, children want the best for their parents. Children want to see that their parents' needs are met in the most compassionate and effective way possible; no child wants to see a parent suffer.

Partners

Communication is a two-way street between you and your partner. Being honest about your emotions can help you draw support from each other. Loving words, hugs, and kisses can bring a sense of comfort and closeness.

Be realistic about demands on your partner, who also may be having a difficult time. Your partner may feel guilty about your illness and any time spent away from you. Another source of stress for a partner is their changing role in the family. For example, your partner may need to tackle new duties, such as paying bills or providing childcare.

Talking things over is especially important if you have been separated by hospitalization for long periods of time. Sometimes in the absence of their partners, patients begin to draw support from, and relate more personally to, members of their health care team. Partners may have a hard time adjusting to this if they sense they no longer are participating in your care.

Your partner also must take time to meet his or her own needs. If these needs are neglected, your partner will have less energy, cheer, and support to give. Try to have other relatives or friends stay with you while your partner attends to the details of daily life. Some time away from each other will refresh both of you. You must remember that you didn't spend 24 hours a day together before your illness. Try, as much as possible, to maintain your relationship in the same way that you did before.

Intimacy

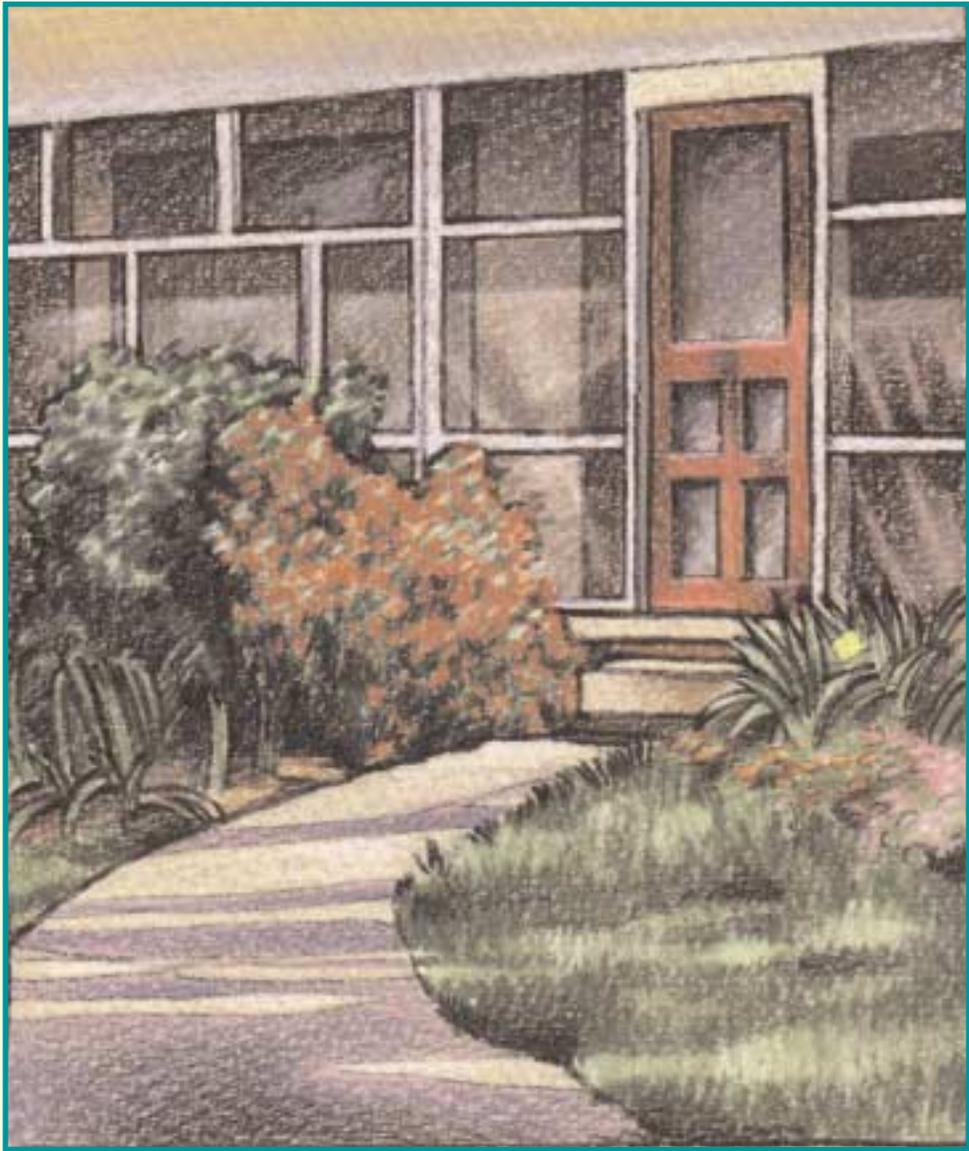
You may find yourself unable to express yourself sexually as you did before because of physical changes and emotional concerns. However, this does not mean that you must deny needs and desires for intimacy. There are many ways to show love and find satisfaction.

Open, honest communication is the key. Re-examining your attitudes about intimacy will help you and your partner maintain the closeness, warmth, and sense of belonging fostered in a loving

relationship. Physical satisfaction can be found in a variety of ways, such as touching, kissing, stroking, and holding.

Sexual problems may stem from feelings about your medical condition or treatment as well as from the condition or treatment itself. With patience and communication between partners, many of these problems can be solved. Understanding why sexual activity may not be the same as before can prevent unrealistic expectations and relieve feelings of self-consciousness or anxiety.

Don't be afraid to seek help or advice. You are entitled to all the information you need or want. You may wish to seek counseling from a professional who specializes in addressing sexuality issues. Your doctor, social worker, or other caregivers also may be able to offer some guidance. Or they may be able to suggest books that deal with sexuality or that offer cancer patients specific information on this subject.



Choices for Care

When dealing with advanced cancer, people may have different personal goals for their care. Some people choose to investigate every medical care option available. Others prefer to focus on the quality of their life, perhaps with treatment to relieve or reduce symptoms, called “palliative care,” but without aggressive treatment of their cancer. Still others may choose not to have any further treatment. Such decisions are deeply personal. If you need to make this type of decision, you may want to carefully review all available options. Your feelings and beliefs (and perhaps those of your family or others close to you) are important to consider. To a great extent, personal goals help determine the level of medical care that is appropriate for you, and the setting in which that care will be provided.

There are different types of services available to patients with advanced cancer. In today's changing health care environment, many patients receive their care at home or in a facility such as a clinic or nursing home, rather than in a hospital. Even when hospital care is an option, patients are often able to obtain care at home as a practical and comfortable alternative to hospital care. When you are considering various options, it's helpful to keep in mind that different types of health care service have different goals. Hospice care and home care are two examples.

Hospice Care

Hospice care is designed to give supportive care to people in the final phase of a terminal illness and focuses on comfort and a person's quality of life, rather than cure. It is intended for patients who no longer desire or can no longer benefit from treatment aimed at curing their cancer. The goal of hospice is to enable patients to be comfortable and free of pain, so that they live each day as fully as possible. Aggressive methods of pain control may be used. Hospice programs generally are home-based, but they

sometimes provide services away from home--in freestanding facilities, in nursing homes, or within hospitals. The philosophy of hospice is to provide support for the patient's emotional, social, and spiritual needs as well as medical symptoms as part of treating the whole person. Hospice caregivers address the needs of the patient and also consider the concerns of those close to the patient.

Hospice programs use a multidisciplinary team approach, including the services of a nurse, doctor, social worker and clergy in providing care. Additional services provided include drugs to control pain and manage other symptoms; physical, occupational, and speech therapy; medical supplies and equipment; medical social services; dietary and other counseling; continuous home care at times of crisis; and bereavement services. Although hospice care does not aim for cure of the terminal illness, it does treat potentially curable conditions such as pneumonia and bladder infections, with brief hospital stays if necessary. Hospice programs also offer respite care workers, people who are usually trained volunteers, who take over the patient's care so that the family or other primary caregivers can leave the house for a few hours. Volunteer care is part of hospice philosophy.

The first hospice program in the United States began serving patients in 1974; today more than 3,000 hospice programs across the country offer comprehensive hospice care. Most insurance plans include hospice as a covered benefit. The National Hospice Organization promotes and monitors the quality of hospice care. For information about hospice concepts, practices, and referral, call the National Hospice Organization at 1-800-658-8898. Your doctor, nurse, or social worker also can provide information on hospice care.

Home Care

Unlike hospice programs, home care services may include treatment that targets the cancer itself, not just the symptoms of the cancer. Some people prefer to have cancer treatments and care in the familiar setting of a home rather than a hospital. Home care is provided through various for-profit and nonprofit private agencies, public and private hospitals, and public health departments. Members of the health care team visit the patient at home. Home health care professionals can provide cancer treatment, pain medications, nutritional supplements, physical therapy, and many complex nursing and medical care procedures. Like hospice care, home care also can manage pain and relieve or reduce other symptoms.

Home care can be both rewarding and demanding for the patient and caregivers. It often changes relationships and requires addressing new issues and coping with unfamiliar details of the patient's care. To help prepare for these changes, patients and caregivers are encouraged to ask questions and get as much information as possible from the home care team.

Depending on your own needs and concerns and those of your family or others close to you, the home care team may include many or all or of the following professionals: nurses or nurse practitioners, social workers, dietitians, physical therapists, pharmacists, oncologists, radiation therapists, and psychologists or psychiatrists. (Some health team members do not make home visits). In addition, many patients find that they need a home health aide to help with bathing, personal care, or preparation of meals. Your primary care physician will remain in close contact with the team and monitor your care through other team members, phone calls, and office visits.

Most insurance plans cover brief home visits from a nurse and some cover having a home health aide several times a week. Although more frequent visits and other home care services are available, such as 24-hour care or respite care performed by trained

volunteers, these services often are not covered by insurance. As always, you need to know exactly what your insurance plan does and does not cover. If you have questions about your insurance coverage, speak to a member of your health care team.

SOME BENEFITS OF HOSPICE AND HOME CARE

Hospice caregivers and home care professionals can help you understand and work through some of the difficult emotional issues that you and your family or others close to you may be experiencing. In this situation, the social worker is an important team member who provides emotional support, assists in planning hospice or home care, and eases the transition between types of care. From the patient's point of view, an advantage to home-based medical services is that family members and friends can be with you and help with your care. As one woman who cared for her mother at home said:

"The times we all were together with Mom, the rest of the family usually sat and talked with her, while I attended to her personal care or coaxed her to eat. [During those times], we quietly seemed to draw strength from each other just by being together."

Insurance Issues

When you are considering different health care services, be sure to check your insurance plan. Insurance coverage may differ depending on the type of care available and its purpose (e.g., comfort versus aggressive treatment). When you call for information about your plan's coverage, it's a good idea to ask for written confirmation of any information you receive by phone. You also may wish to discuss specific options, such as hospice care and home health care, with your nurse, doctor, social worker, or clergy, as well as your insurance company.

Making Treatment Decisions

It is your right to make decisions about your treatment. It is also important for you and those around you to realize that these decisions may change over time. Family, friends, and caregivers may find it hard to accept, but for some patients, trying to cure their cancer is no longer the goal. Quality of life becomes more important. Other patients may want to try every available drug or treatment in the hope that something will be effective. Either way, it is up to you. Many patients turn to family members, friends, or caregivers for advice. But the decision about how much or how little treatment for you to have is yours. Sometimes a patient is unable to make this decision, due to severe illness or change in mental condition. That is why it is important to make your wishes known in advance (See Advance Directives, page 32.)

Even though the decisions are yours to make, your family or those close to you should not be left out. Families and loved ones are often the most important source of support for patients at this time. Patients are encouraged to establish a durable power of attorney and a living will so that their wishes are known by family members and the health care team. These options are discussed on pp. 32-33.

Refusal of treatment does not necessarily mean immediate decline and death; however, a decision to refuse treatment should be based on your feelings about life, death, and the benefits and side effects of treatment. If you decide to stop treatment, you can still receive pain medication and treatments to reduce the symptoms of your disease. This is called palliative care, and its primary focus is helping you remain as comfortable as possible. Remember: You can change your mind and ask to resume more aggressive treatment. If you do, however, be aware that such a decision may raise insurance issues that you will need to explore with your health care plan.

Your doctors will, almost certainly, offer information and advice to help you decide whether or when to stop treatment. Many religious groups have issued statements about the decision to end treatment. You may want to explore the position that your

religious group takes on this issue. Contact a member of the clergy or other counselor if you would like more information. In the end, you are the only one who can decide what is best for you.

Patients' Rights

You have other rights, too. You are entitled to complete information about your illness and how it may impact on your life, and you have the right to share or withhold that information from others. You also should be informed about any procedures and treatments that are planned, the benefits and risks, and any alternative treatments that may be available. You may be asked to sign an "informed consent" form, which includes this information. Before you sign such a form, read it carefully and ask your doctor any questions you might have.

The Patient Self-Determination Act

A Federal law, the Patient Self-Determination Act (PSDA), requires all medical care facilities receiving Medicare and Medicaid payments to inform patients of their rights and choices in making decisions about the type and extent of their medical care. The PSDA also requires medical care facilities to give patients information about living wills and power of attorney, which are described below. For more information about the PSDA, contact any hospital or medical care facility in your area.

Advance Directives: The Living Will and Durable Power of Attorney for Health Care

All states allow people to delegate some medical decision-making rights through "advance directives," but state laws differ considerably. The two forms of advance directives are a living will and a durable power of attorney for health care.

A living will is a legal document, which has been properly witnessed by an authority (notary), that allows you to state, in writing, that you do not wish to be kept alive by artificial means

or heroic measures. It is a recognized statement of your right to refuse treatment and has been upheld in court. If you decide to prepare a living will, be sure to talk with your doctor, nurse, or lawyer to identify and define terms that may be important to your future medical care, such as "artificial means," "heroic measures," and "code status."

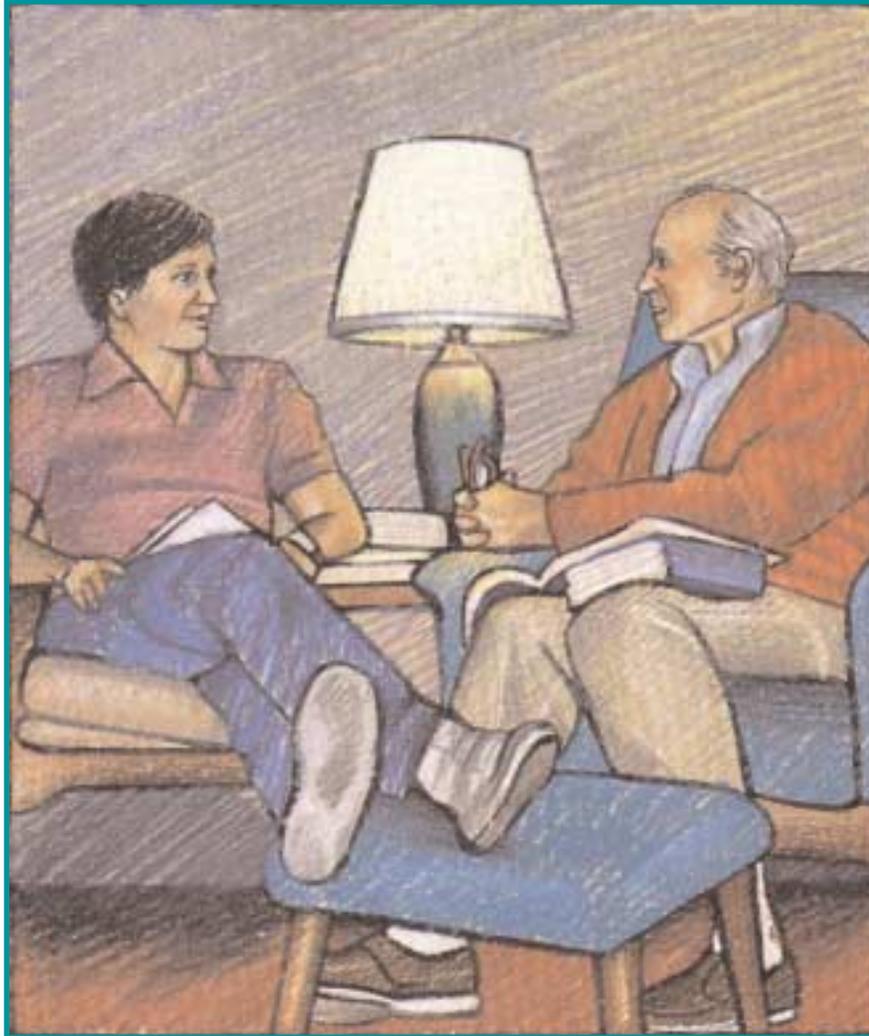
You also may want to consider creating a durable power of attorney as a health care proxy (that is, a person who will stand in your place to make medical decisions). This legal document allows you to appoint someone who can make decisions for you about your medical care if you can no longer do so. Choose a person who knows how you feel about specific treatments and who is familiar with any religious considerations that need to be taken into account. And make sure that the term "durable" appears in the power of attorney document you prepare. (A power of attorney can also delegate authority for financial and property management.)

HOW TO FIND OUT ABOUT YOUR STATE'S LAWS

Each state has its own laws concerning living wills and durable powers of attorney, and these laws can vary in important details. It is possible that a living will or power of attorney signed in one state may not be recognized in another. You need to be aware of this possibility if you move to another state or enter a hospital in a state other than the one in which you live.

Call Choices in Dying, Inc., a nonprofit educational organization, at 1-800-989-WILL to learn how to obtain a copy of the living will used in your state and to learn more about a durable power of attorney for health care (health care proxy). There is a small fee for obtaining the document. You also can contact your state health department for this information.

If you sign a living will or a durable power of attorney, tell everyone close to you that you have these documents and give them copies. Your health care team and lawyer, if you have one, also should be informed and given copies. This information will help ensure that your wishes are carried out.

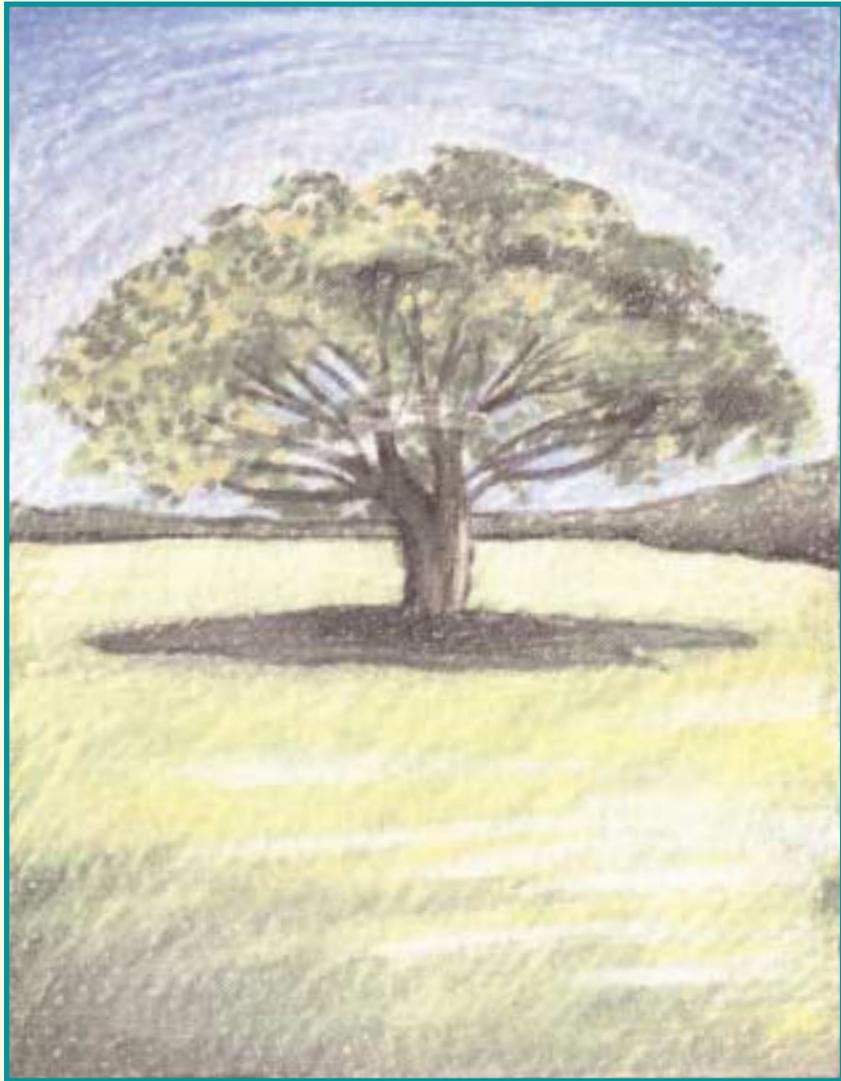


Planning for Your Family

Careful planning reduces the financial, legal, and emotional difficulties your family and friends face after your death. Though it is difficult, discussing practical matters now, such as wills and debts, can eliminate many problems later. Your early decisions also help relieve unspoken family worries. Advice from professional advisers, including lawyers, clergy, social workers, and insurance company representatives, can help you make these important decisions.

You may want to help your family plan a funeral or memorial service that has your personal and special touch. Talk with your family and clergy about how you would like to be honored and remembered. Your choice of music, readings, and participants will speak your personal message to those gathered to remember you.

You can help your family by organizing records, documents, and instructions they will need. If you cannot gather all of these items, make a list of where they are located. The papers should be kept in a fireproof box or with your lawyer. If they are kept in your safety deposit box, be sure a family member or friend has access to the box so that papers can be removed when needed. Although the original documents must be used for any legal purposes, you may want to make copies for family members. The forms at the end of this brochure can serve as guides for collecting your records.



Conclusion

We hope this booklet has been helpful to you and those close to you. Our intention has been to give you some practical information and to encourage discussion with family and friends.

Open communication offers a chance to learn one of life's most important lessons. As one cancer patient said:

“We can choose to wait for death, or we can choose to live until we die. Knowing that death is in the near future is no reason to give up on the life we have today.”

We hope that this booklet will help you face this time in your life. Try to remember that even when there seems to be little hope, there are ways to fight feelings of hopelessness and to acknowledge the good things around you.

Try to keep in mind that survival statistics are just numbers. They are no guarantee that you will die at a certain time. In fact, the numbers that should mean the most to you — and perhaps to all of us at any time of life — are those that measure the good days, the comfortable nights, and the hours of happiness and joy, however you find them.

National Cancer Institute Information Resources

You may want more information for yourself, your family, and your doctor. The following National Cancer Institute (NCI) services are available to help you.

Telephone

CANCER INFORMATION SERVICE (CIS)

Provides accurate, up-to-date information on cancer to patients and their families, health professionals, and the general public. Information specialists translate the latest scientific information into understandable language and respond in English, Spanish, or on TTY equipment.

Toll-free: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Internet

This Web site may be useful:

<http://cancer.gov>

NCI's primary Web site. Contains information about the Institute and its programs, cancer issues, and clinical trials.

PERSONAL CHECKLIST

Use the following personal checklist as a guide for identifying, collecting, and organizing important records, documents, and instructions. Use the Personal Inventory form on the next few pages to fill in more details about the documents and records that you have.

Personal checklist for _____.
(your name)

For a quick reference, place a check in the box next to the items that you have. You may have all, several, or just one or two of the items listed below. If you feel that some of the unchecked items may be important to you and/or your family, it may be helpful to talk with your family, doctor, clergy, lawyer, or insurance agent about the specific benefits of that item before making a decision.

- Birth certificate
 - Social Security number
 - Living will
 - Durable power of attorney for health care
 - Life insurance
 - Health insurance
 - Accident insurance
 - Pension plan(s)
 - Bank account(s)
 - Safe deposit box
 - Automobile(s)
 - Real estate/rental papers
 - Others _____
-
-

PERSONAL INVENTORY

Name _____ Date _____

Address _____

Date of Birth _____ Place of Birth _____

Social Security Number _____

Next of Kin: Name _____

Address _____

Durable Power of Attorney (health care) _____

Employer

Name _____

Address _____

Company Benefits _____

Personal Papers (birth certificate, living will, etc.)

Item	Location
------	----------

_____	_____
_____	_____

Insurance

Company (name and address)	Policy Number
----------------------------	---------------

Life: _____	_____
-------------	-------

Health and Accident: _____	_____
----------------------------	-------

Automobile: _____	_____
-------------------	-------

Other: _____	_____
--------------	-------

Banking Papers (include pension plans, if any)

Kind of Account Number	Bank Name/Address	Account
------------------------	-------------------	---------

_____	_____	_____
_____	_____	_____

Other Accounts (include pension plans, if any)

Type	Where	Account Number
Safe Deposit Box	_____	_____
_____	_____	_____

Automobiles (make, model, year) _____

Real Estate Papers _____

Personal Items of Value _____

Counselors Who Can Help With My Affairs

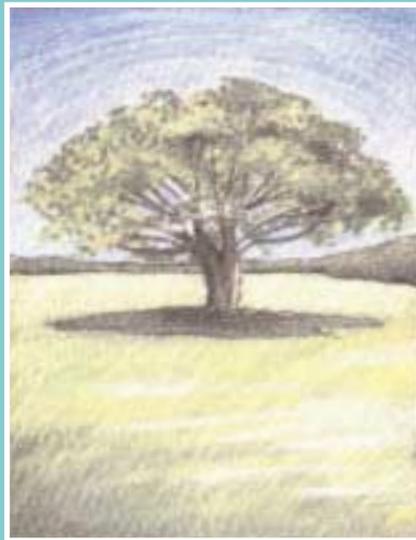
Attorney _____
Insurance Agent _____
Doctor _____
Clergy _____
Other (broker, business associate, accountant) _____

Funeral Arrangements _____

Special Requests _____

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